Understanding barriers for pregnant women, especially those who might be HIV positive, to deliver at a clinic – A research case of Kuajok Primary Health Care Clinic in Gogrial west county – Warrap State: South Sudan

by

Leonardo Shamamba Kinyungu

Assignment presented in partial fulfillment of the requirements for the Master degree of Philosophy (HIV/AIDS Management) at Stellenbosch University

Supervisor: Prof JCD Augustyn
Faculty of Economic and Management Sciences
Africa Centre for HIV/AIDS Management

March 2013

Declaration

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

March 2013

ABSTRACT

Home deliveries are still a big reality in the community surrounding the Kuajok PHCC due long distance to reach health facilities, lack of financial resources, poor transportation system and road infrastructures, traditional habits and limited awareness about health issues including HIV/AIDS, thus jeopardizing PMTCT service provision. To overcome this problem, the study recommends to scale up awareness activities within the community. Looking at the current volatile situation in South Sudan, humanitarian actors need to support the young South Sudan Government with low cost innovation approaches using local resources to address most of the above-mentioned issues at least for a certain period of time while the Government is getting stronger to take over in the long run for sustainability.

OPSOMMING

Dit is steeds ‘n realiteit dat geboortes tuis gehanteer word in die Kuajok PHCC veral as gevolg van lang afstande vanaf klinieke, ‘n swak vervoerstelsel en ekonomiese oorwegings.

Tradisionele gebruike en ‘n groot onkunde oor die verspreiding van MIV/Vigs veroorsaak dat die PMTCT programme in ‘n groot mate oneffektief in hierdie gebiede is.

Ten einde bogenoemde probleem te probeer voorkom, stel hierdie studie voor dat die bewustheidsvlakke ten opsigte van MIV/Vigs opgeskerp moet word in hierdie afgesonderde gemeenskappe. Die probleem in Suid-Soedan word verder bemoeilik deur deurlopende konflik in daardie gebied.

Die studie stel voor dat die regering van Suid-Soedan fondse beskikbaar moet stel ten einde doeltreffende bewusmakingsprogramme in die plattelandse gebied van Suid-Soedan op ‘n volhoubare wyse aan te bied.

ACKNOWLEDGEMENTS

I would like to express my deep gratitude to Professor Johan Augustyn, my research supervisor, for his valuable and constructive guidance during the whole process of this research. I would also like to thank Dr. Christel Troskie-de Bruin and Dr. Ruth Albertyn for their advice and assistance provided for research proposal designing. I would also like to extend my thanks to the entire Africa Centre for HIV/AIDS Management team members including Professor Jan du Toit, Ms. Laas Anja, Ms. Farao Bianca, Ms. Arlene Willets and Mr. Burt Davis for their patient guidance, enthusiastic support during the course of this research. My grateful thanks are also extended to the Stellenbosch University IT department members for their prompt support in dealing with issues related to the effective use of Moodle.

I would like to express my very great appreciation to the South Sudan Warrap State Primary Health Care Director, Mr. Michael Nyang and Mr. Stephen Mururu for the help provided to meet and get clearance for data collection from relevant authorities both at the Warrap State Ministry of Health and the Kuajok Primary Health Care Centre. I wish to acknowledge the help provided by the Acting Medical Director for the Kuajok Primary Health Care Centre, Dr. Barach and Ms. Rahab in facilitating data collection process. I would like to offer my special thanks to Ms. Regina Achot and Ms. Ajok Aken Maluil for their help in translation during data collection.

My special thanks are extended to my fellow colleagues for the encouragement and useful discussions on Moodle during this research.

Finally, I wish to thank very much my wife for her unconditional support and encouragement throughout my study.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

ACRONYMS

AIDSTAR – AIDS Support and Technical Assistance Resources

ANC – Antenatal Care

ART – Anti Retroviral Therapy

BCC – Behavior Change Communication

GOSS – Government of South Sudan

HIV/AIDS – Human Immunodeficiency Virus / Acquired Immunodeficiency Syndrome

IGAD – Inter-Governmental Authority on Development

IMC-UK – International Medical Corps United Kingdom

IRC – International Rescue Committee

MCNH – Maternal Child and New-born Health

MDG – Millennium Development Goals

MTCT – Mother to Child Transmission

NGO – Non Governmental Organization

PHCC – Primary Health Care Clinic

PLWHA – People Living with HIV/AIDS

PMTCT – Prevention of Mother to Child Transmission

RSS – Republic of South Soudan

TBA – Traditional Birth Attendant

UNAIDS – Joint United Nations Program on HIV/AIDS

UNICEF – United Nations Children's Fund

UNGASS – United Nations General Assembly Special Sessions

VCT – Voluntary Counseling and Testing

WES – Western Equatorial State

WHO – World Health Organization

CHAPTER 1: INTRODUCTION

1.1 Background

In South Sudan, low antenatal care attendance is common (Thiam, 2012), the antenatal care coverage is 16% (Michael, Andreini, Mojidi, Pressman, Rajkotia & Stanton, 2007) and data suggests that only 15% of births took place in a formal health facility in 2006 (International HIV/AIDS Alliance, 2009). With its predominantly rural population, at least 90% of births occur far from urban centers where clinics are based (Gordon, 2011) and only about 10% of them occur in the presence of a midwife or person with midwifery skills (Michael & Garnett, 2010 – 2012).

During antenatal care sessions, pregnant women usually receive valuable information related to their pregnancy, any risks associated and how to deal with each of them. At this occasion, pregnant women are educated about setting delivery plan. They also receive information related to the importance of delivering under the supervision of trained health care personnel and preferably at a clinic which has the capacity to provide appropriate services. Besides, the Government of South Sudan – GOSS (Ministry of Health) has also introduced the policy to provide couples with Voluntarily Counseling and HIV Testing (VCT) if available as well as to pregnant women in order to prevent HIV transmission from mother to child. The government policy also suggests discussing family planning if one of the partners is positive. The objective is to subsequently put HIV positive pregnant women in the Prevention of Mother to Child Transmission (PMTCT) program to reduce vertical transmission of HIV. The PMTCT program takes care of both the mother and the child during pregnancy, during labor and delivery and in the post-partum period, especially during breastfeeding phases. For the PMTCT program to be effective, HIV positive pregnant women need to stay in the program throughout at all the above mentioned stages.

Ilona Howard (as cited in Gordon, 2011), who worked in South Sudan from 2007 to 2010 for International Rescue Committee (IRC) and is now program officer for International Medical Corps United Kingdom (IMC – UK), describes an average birth process: "women usually go back to their original family home, where they then give birth with the help of their mother, and a Traditional Birthing Assistant (TBA)". TBAs are women from the local village or town, respected among communities because of their age and experience, and often called upon by relatives when an expectant mother is about to give birth. For these women, transport to a maternity clinic is often unaffordable, as are food costs during the stay - another reason why TBAs are so relied upon. Yet, with little or no midwifery training, TBAs tend to be unable to cope in the face of complications or an emergency. Whilst there have been some training programs for TBAs, their lack of basic

education means that "training TBAs will not improve maternal mortality rates, and we must be realistic about what impact they can make". Of course, in a country where available support for mothers is so limited, TBAs should still be given a role in birth and delivery. As long as women continue to have home births without skilled midwives, and the availability of effective public clinics remains limited, there is little chance of major improvements being made.

The extent of the prevalence of HIV and AIDS in South Sudan is not known, but the 2009 antenatal care (ANC) surveillance estimates that the current HIV prevalence in South Sudan is three per cent, and wide disparities between geographical locations exist, with some areas like Western Equatorial State (WES) having levels as high as 7.2% . Areas along the borders with neighboring countries, as well as along major transport corridors, are believed to have a significantly higher prevalence rate. With an improved security situation in South Sudan, mobility has been restored and HIV/AIDS prevalence rates are likely to increase due to heightened cross-border travel to countries with higher HIV prevalence (United Nations Children's Fund – UNICEF, 2012). According to International HIV/AIDS Alliance (2009), in South Sudan mother to child HIV transmission is the greatest source of HIV infection in children below 15. With no intervention 24-45% of babies born to HIV-infected mothers will acquire the virus. Rates of Mother to Child Transmission (MTCT) of HIV vary from 15-30% without breastfeeding and can reach as high as 30-45% with prolonged breastfeeding.

Ways to ensure HIV positive pregnant women are adherent to PMTCT principles may include strong counseling services, patients education, collaborative planning, Behavior Change Communication (BCC) and addressing any other barrier to the approach.

1.2 Research problem

The World Health Organization - WHO's PMTCT Strategic Vision 2010–2015 has the objective of preventing mother-to-child transmission of HIV to reach the United Nations General Assembly Special Sessions - UNGASS and the Millennium Development Goals - MDGs by increasing access to quality PMTCT services and integrate these services with Maternal, Child and New-born Health (MCNH) and sexual and reproductive health programs (WHO, 2010).

''Unfortunately, the PMTCT is jeopardized in South Sudan (case of the Kuajok Primary Health Care Clinic - PHCC) due to high rate of HIV positive pregnant women who are not delivering at the health facility'' said Stephen Mururu (Senior nursing officer under the Republic of South Sudan – RSS/ Inter-Governmental Authority on Development – IGAD regional project) and Regina Achot (certified nurse) at the Kuajok PHCC. Not only the rate of clients who register for antenatal care is

low, but also barriers for pregnant women, especially for those who might be HIV positive to deliver at the clinic are not well known and/or documented.

1.3 Research question

The research question set for this study was to identify what are the barriers for pregnant women and especially those who might be HIV positive to deliver at the clinic?

1.4 Significance of the study

This study is conducted to inform about barriers that impede delivery by skilled personnel and proper PMTCT of HIV related to the place where pregnant women deliver and, therefore will suggest best practices to adopt. The primary beneficiaries of this study are, on one hand, children born without attendance by skilled personnel and especially those from HIV positive mothers; and on the other hand, women at risk of complication during their pregnancy. They will benefit in such a way results from the study will suggest strategies to minimize unsafe deliveries as well as new HIV infection in children. The study will benefit the entire family since the outcome will also suggest how to have a healthy family despite parents' HIV positive status. It will propose at the same time ways to minimize economic burden on the family related to complications of pregnancies. Moreover, this study will also benefit the health care providers since the outcome will suggest ways to reduce the number of complicated deliveries and HIV pediatric cases to deal with in the future.

1.5 The aim of the research

The aim of this research is to identify what are the barriers for pregnant women in general and for those who might be HIV positive, in particular, to deliver at the clinic in order to develop appropriate strategies to address this issue.

1.6 Objectives

The objectives set for this study were:

1. To establish the current attitudes among pregnant women in general and especially those who might be HIV positive related to delivering either at the clinic or at home
2. Identify current practices among pregnant women in general and especially those who might be HIV positive related to delivering
3. Identify the reasons for such practices

4. Establish appropriate approaches to address issues discovered

CHAPTER 2: LITERATURE REVIEW

During health and HIV/AIDS cluster meetings in South Sudan, the question about low utilization rate of reproductive health facilities and PMTCT services is always on the agenda and it has been a public health concern for the Ministry of Health, donors and International NGOs operating in the sector. Solutions to overcome this issue have been hard to find among different actors despite efforts being put in place. Getting this problem solved will certainly contribute to the Joint United Nations Program on HIV/AIDS – UNAIDS's vision of eliminating new HIV infection among children by 2015 and obviously also contribute to the reduction of maternal and child mortality.

2.1 Lack of Knowledge and awareness

Lack of Knowledge and awareness about health issues can be one of the major barriers for the community to properly access MCNH and PMTCT services. Knowledge and awareness of HIV is very low in South Sudan, with only 45% of women between 15 and 45 having heard about it and 70% unaware of the three main forms of prevention. The majority of women (68% of 15-49 year-old women) don't have any knowledge that HIV can be transmitted from a mother to a child and data suggests that only 15% of births took place in a formal health facility in 2006 (International HIV/AIDS Alliance, 2009). According to UNICEF (2012), this situation is compounded by existing high levels of low school enrolment rates, a health system with weak outreach capacity, and the low status of women and girls in society. South Sudan has not had widespread dissemination of information on HIV and AIDS and therefore comprehensive knowledge about HIV transmission and prevention (11.3% among young people aged 15-24 years), as well as mother-to-child transmission, is very low (15.1%).

2.2 Socio-economic factors

Socio-economic factors can also affect proper delivery of MCNH and PMTCT services. Poverty is not only a cause but an effect of HIV/AIDS pandemic. The HIV and AIDS epidemic continues to be a major challenge both to public health and the socio-economic development of South Sudan (UNICEF, 2012). It makes poor people poorer rendering them desperate and without quality care. The poor People Living with HIV/AIDS – PLWHA cannot access adequate clinical care because they cannot afford to pay for medical services. Medical centers that offer free medical services to the PLWHA cannot improve quality because of the large numbers of PLWHA. They are forced to seek for free medical services because they cannot afford to pay for them elsewhere (Kamau, undated).

2.3 Stigma

HIV stigma forms a backdrop of most societies in the third world and poses a threat for patients to access HIV health care services. Stigma undermines efforts aimed at managing and preventing HIV. Interestingly, most experiences of HIV stigma take place within health care facilities. For instance, health workers may stigmatize patients, but at the same time health care workers may also experience stigma by virtue of the fact that they work with HIV & AIDS patients. This can have adverse consequences for HIV & AIDS programs, as patients and health workers would not want to be associated with HIV & AIDS health care service due to the fear of stigma. A study conducted by Sprague, Chersich and Black (as cited in Phetoe, 2011) found that often women feared to be tested positive due to fear of being stigmatized. In addition, due to fear of being stigmatized, some women accessing health care services denied a positive test result and some denied being tested for HIV. The study also found that some mothers would not bring the baby back to the clinic for HIV tests or for laboratory results for the HIV status of the baby. These cases resulted in some mothers not being able to access or adhere to PMTCT, resulting in missed opportunities to save babies from HIV infections. Sprague et al. further found that stigma, along with other dysfunctional aspects evident in within health care systems, posed as challenges against mothers adhering to PMTCT. Testing and sometimes disclosure were part of attending PMTCT services (mandatory or not); hence, it might deter people from accessing them. One prominent reason usually given is that HIV and AIDS are associated with negative qualities such as “loose morals” and being a “prostitute” (Sondergaard, Hald, & Lazarus, 2010). As discussed above, mothers frequently choose not to disclose their HIV status due to fear of stigma. HIV stigma poses a threat to withdrawal of social support from families and friends for an HIV positive mother and her baby. These mothers are often not supported by families and the community due to their “peculiar” practices they implement in caring for their babies. Decreased social support may result in loss of economic support, emotional support and moral support from potential and existing sources due to stigma (Phetoe, 2011).

2.4 Integrated PMTCT and MCNH challenges

According to AIDS Support and Technical Assistance Resources – AIDSTAR-One (2011), many of the challenges to integration of PMTCT and MCNH programs are endemic within health care

systems in developing countries. PMTCT integration poses specific challenges, including the following:

2.4.1 Stigma and discrimination:

As mentioned above, providers may hesitate to offer services to women living with HIV. Also, clients frequently avoid attending facilities that are known to provide HIV services (Israel and Kroeger as cited in AIDSTAR-One, 2011)

2.4.2 Socio-cultural and gender-related barriers:

According to Colin and Paperwalla (as cited in Cook Ross Inc., 2010), pregnancy is seen as a normal bodily function rather than an illness. Therefore women may not feel the need to seek prenatal care, unless something is wrong with the pregnancy. Religious beliefs, cultural customs, gender inequities, gender norms, gender-based violence, poverty, and power relations between men and women need to be addressed—both at the facility and policy levels—for successful integration (AIDSTAR-One, 2011);

2.4.3 Funding weaknesses:

PMTCT services are usually funded separately from MNCH programs, and very often both programs are underfunded—especially at low-level facilities. This makes it difficult to fully integrate PMTCT as a core component of maternal and child care, and takes a particular toll on remote and very poor communities (Druce and Dickinson as cited in AIDSTAR-One, 2011). Additionally, integration will not solve the problem of underfunding; managers need to examine the true cost of services and provide resources to support them (WHO 2008 as cited in AIDSTAR-One, 2011).

2.4.4 Human, logistical, and technical resources:

Due to the impact that HIV & AIDS has had on the third world countries, health care systems are faced with a lot of structural challenges in responding to prevention, care and treatment of the pandemic. Health care systems experience the reality of overcrowding, staff shortages and having limited infrastructure. A combination of these factors, within the context of high HIV stigma, undermines the effectiveness of efforts to address HIV. These conditions prove to be inconvenient and discomforting for patients, as they may experience their rights to privacy and confidentiality being undermined. The lack of privacy and confidentiality that may be encountered by patients

could lead to personal information being divulged without the permission of the patient. Efforts have been made to improve accessibility of HIV services, which include exclusive departments, cues or buildings that provide specialized care and treatment for people living with HIV, such as the Wellness Clinics and special cues for ART's and PMTCT. In some settings, these efforts involve having color coded files to identify patients or babies of patients infected with HIV. These initiatives may have improved the HIV patients' access to services but has tended to involuntarily disclose their status to others. Patients may feel uncomfortable accessing these facilities due to fear that other community members may identify and ostracize them or their families. These settings pose a threat to women to access and adhere to PMTCT due to fear of stigma (Phetoe, 2011). As mentioned above, many health systems are already struggling with severe shortages of skilled providers, equipment, and supplies. This results in providers being overwhelmed with multiple responsibilities for the services they already provide. Because integration will potentially increase this load, it is critical that additional resources, or specific strategies for supporting providers and establishing a reliable supply chain, be an integral part of the planning and implementation (Israel and Kroeger as cited in AIDSTAR-One, 2011). South Sudan itself is a country in its infancy. Independence was declared since about two years on July 9, 2011 and before it can even begin to make any measurable improvements in maternal health, South Sudan needs to grow in other areas. In a country the size of France and Spain combined, but with only 50km of paved road, and very few of these outside the capital Juba, when complications arise, many women are often unable to reach the facilities necessary for a safe birth. With its predominantly rural population, at least 90% of births occur far from urban centers where clinics are based. Most often, women use anything available - from bicycles to donkeys, being carried on a stretcher to hitching a lift in car - to get to a clinic. And even then it may still be too late (Gordon, 2011).

Despite good intentions and commitment from providers, prevention-of-mother-to-child-transmission of HIV (PMTCT) services can be difficult for pregnant women to access, despite the provision of free health services for women and children. As a result of conflict in South Sudan, health systems are weak; in 2007, the MOH reported that Southern Sudan had just eight sites providing PMTCT services which were integrated into ANC services. There are huge practical challenges in delivering effective PMTCT services in South Sudan, not least addressing the acute shortages of HIV testing kits, antiretroviral prophylaxis for mother and exposed child, safe delivery services and infant feeding advice (International HIV/AIDS Alliance, 2009). Sarah Goldsmith explains (as cited in Gordon, 2011): "one of the main reasons women don't use clinics is also that they don't have confidence in them and are treated poorly when they go there." Poor roads, an underdeveloped transport system, poor telecommunications and other socio-economic contexts can

present a formidable barrier to the provision of PMTCT and MCNH services. Improvement in services to rural areas will require creative thinking, perhaps including the use of mobile services and the development of community structures, such as contributions to community health education by traditional birth attendants and local volunteer groups (Skinner, Mfecane, Gumede, Henda & Davids, 2005).

Maternal mortality is not only a medical problem. It is a problem inextricable from the lack of infrastructure, insufficient government-provided health staff and facilities, failures in education and, essentially, inequality in the status of women. Unless women are acknowledged and valued beyond their child-bearing capacity and introduced to family-planning methods and education, the trajectory of maternal mortality rates will only see, at best, slow positive change (Gordon 2011). The use of traditional birth attendants (TBAs) is common in the South Sudanese context. In settings of high HIV prevalence, many HIV positive women may deliver with a TBA thus preventing an opportunity for prevention of mother to child transmission (PMTCT). Issues hindering success of incorporating TBAs in PMTCT service delivery include lack of transport for the delivering mother; lack of sustainable source of income influencing TBAs to continue conducting deliveries; non-disclosure of status by HIV positive women; inability to determine whether nevirapine is taken and inability to tell if referred women reach health facilities or not (Kabondo, Zimba, Kamanga, Hamela, Mofolo, Bulla, Martinson, Hoffman, Van der Horst & Hosseinipour, 2009).

CHAPTER 3: METHODOLOGY

Both quantitative and qualitative methods were utilized for this research to cover socio-cultural, accessibility and economic dimensions. The survey targeted 30 pregnant women aged 18 years and above randomly selected during antenatal clinic sessions at the Kuajok Primary Health Care Clinic - PHCC was conducted after the provision of ethical clearance by the Stellenbosch University Research Ethical Committee. As a measuring instrument, own developed questionnaire was administered to the target group. Limited open-ended questions were self-administered with the assistance of a translator. Focus group discussions were conducted with two groups of an average of six pregnant women attending antenatal clinic in each group and individual interviews were also held with two key informant personnel at the Kuajok PHCC for triangulation. Data entry and analysis was done using EPI INFO 7 and Excel 2010.

CHAPTER 4: RESULTS AND DISCUSSION

4.1 Demographic data

The distribution by age groups of pregnant women who participated in the survey is presented in the Table 4.1 below:

Table 4.1

Distribution of respondents by age groups

Age Group	Frequency	Percent	Cum. Percent	95% CI Lower	95% CI Upper
18 - <24	11	37%	37%	20%	56%
24 - <30	10	33%	70%	17%	53%
30 - <36	8	27%	97%	12%	46%
36 - <40	1	3%	100%	0%	17%
TOTAL	30	100%	100%		

In total, 30 pregnant women attending antenatal clinic at the Kuajok Primary Health Care Clinic have been interviewed. Most of respondents (70%) are between 18 and less than 30 years old while the mean age of the participants is 26 years.

The information given above are graphically presented in Figure 4.1 below:

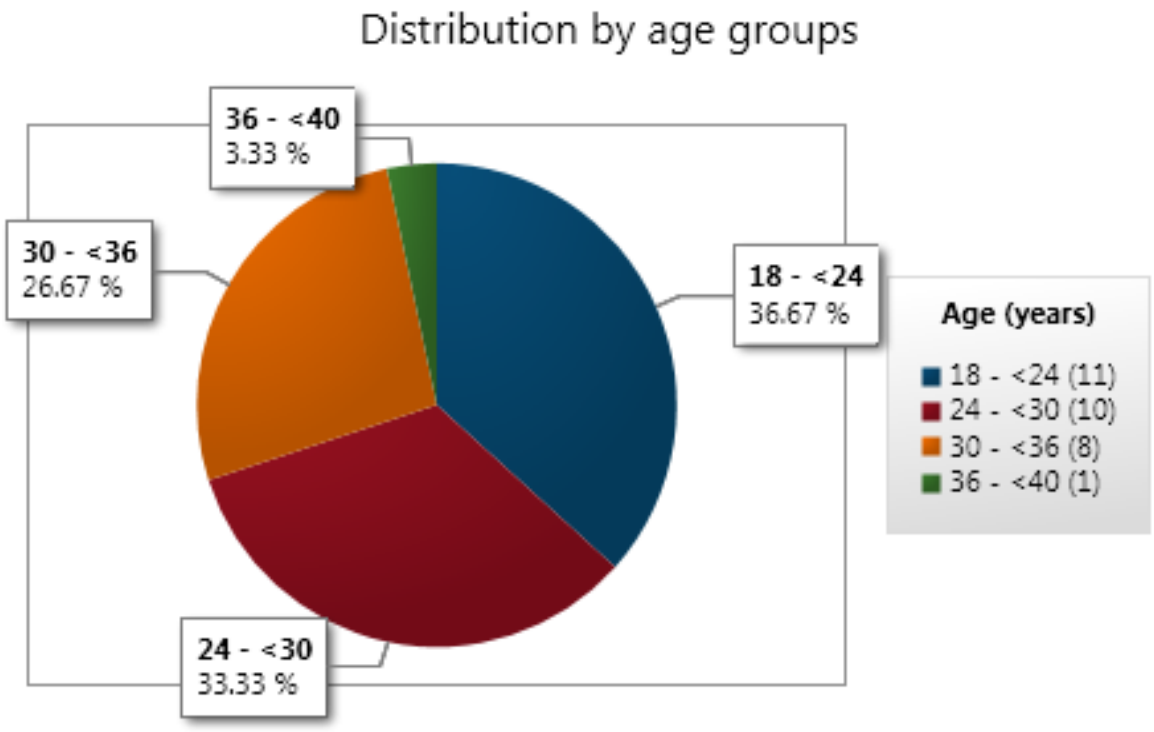

Figure 4.1. Distribution of respondents by age groups

4.2 Attitudes and practices among pregnant women related to place for delivery

The attitudes and practices among pregnant women who participated in the study and related to place of delivery are given in Tables 4.2, 4.3 and 4.4 below:

Table 4.2

Distribution of answers related to locations where deliveries usually take place

Location where deliveries usually take place	Frequency	Percent	Cum. Percent	95% CI Lower	95% CI Upper
At home	20	67%	67%	47%	83%
At health facility	10	33%	100%	17%	53%
TOTAL	30	100%	100%		

According to pregnant women interviewed during the survey, 67% affirm that most pregnant women in the community surrounding the Kuajok PHCC usually deliver at home. 100% of respondents in Focus Group Discussions and key informants at the Kuajok PHCC confirmed the same information. This is also close to what is above highlighted through the literature where data suggests that only 15% of births took place in a formal health facility.

The information given above are graphically presented in Figure 4.2 below:

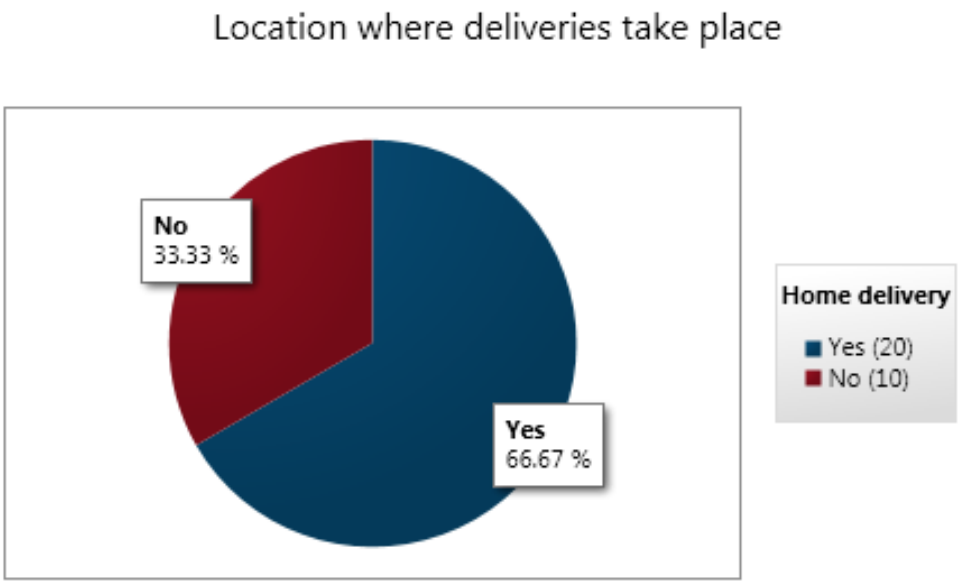

Figure 4.2. Distribution of respondents according to their statement about location where deliveries take place

The distribution of pregnant women according to delivery prior to the current pregnancy is given in Table 4.3 below:

Table 4.3

Distribution of pregnant women according to delivery prior to the current pregnancy

Delivered prior to the current pregnancy	Frequency	Percent	Cum. Percent	95% CI Lower	95% CI Upper
Yes	24	80%	80%	61%	92%
No	6	20%	100%	8%	39%
TOTAL	30	100%	100%		

From all the pregnant women attending the Kuajok PHCC and who participated in the survey, 80% of respondents affirmed have delivered prior to the current pregnancy. Among these ones, 46% affirmed have delivered at home their last born.

The information given above are graphically presented in Figure 4.3 below:

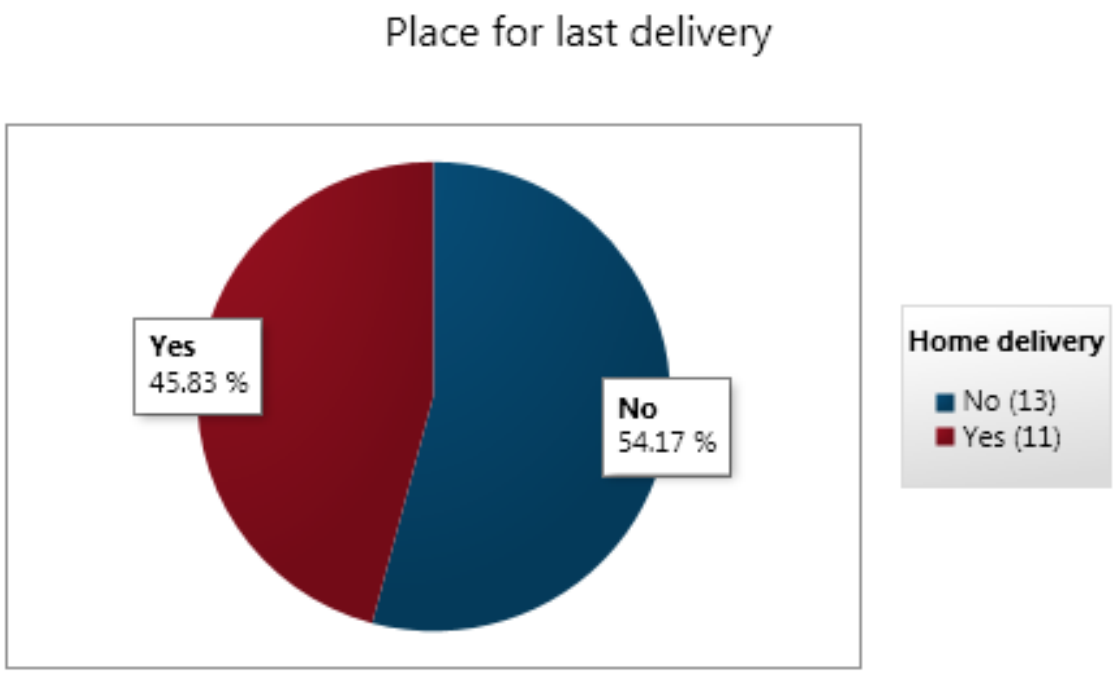

Figure 4.3. Distribution of respondents according to the place they went for the last delivery

The distribution of pregnant women related to the place they wish to deliver next time is given in Table 4.4 below:

Table 4.4

Distribution of pregnant women according to place where they wish to deliver next time

Preferred place for next delivery	Frequency	Percent	Cum. Percent	95% CI Lower	95% CI Upper
At health facility	29	97%	97%	83%	100%
At home	1	3%	100%	0%	17%
TOTAL	30	100%	100%		

Despite the fact that many deliveries are currently taking place at home, almost all pregnant woment who participated in the survey (97%) would prefer to have their next delivery at a health facility. It therefore looks like this is achievable, at least for those attending antenatal care sessions, if there is no barriers for that.

The information given above are graphically presented in Figure 4.4 below:

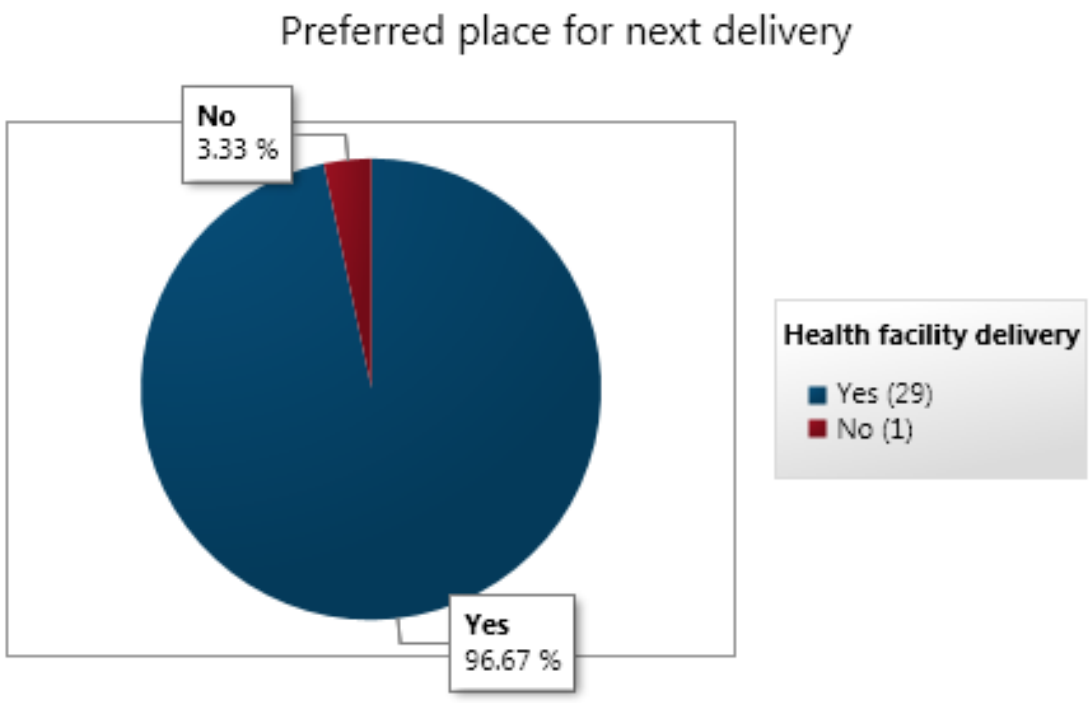

Figure 4.4. Distribution of respondents according to where they prefer to deliver next time

4.3 Reasons evoked to explain home deliveries

The five top reasons evoked to explain the cause of high level of home deliveries in the community according to pregnant women who affirmed the information include: (1) long distance to reach the nearest health facility – 80% of respondents. 36% of respondents affirm have delivered they last born at home due to long distance issue; (2) lack of financial resources – 55% of respondents. 18% of respondents affirm have delivered they last born at home due to financial resources issue; (3) lack of transportation means – 35% of respondents; (4) sometimes deliveries occur abruptly – 30% of respondents. 27% of respondents affirm have delivered they last born at home because it happened abruptly; and (5) lack of roads – 25% of respondents.

Some of these considerations are also confirmed through the literature above: according to Gordon (2011), in a country the size of France and Spain combined, but with only 50km of paved road, and very few of these outside the capital Juba, when complications arise, many women are often unable to reach the facilities necessary for a safe birth. With its predominantly rural population, at least 90% of births occur far from urban centers where clinics are based. Most often, women use anything available - from bicycles to donkeys, being carried on a stretcher to hitching a lift in car - to get to a clinic. And even then it may still be too late. Sarah Goldsmith (as cited in Gordon, 2011) reinforced this by saying that poor roads, an underdeveloped transport system, poor telecommunications and other socio-economic contexts present a formidable barrier to the provision of PMTCT and MCH services in South Sudan.

Results from Focus Group Discussions and interview with key informants at the Kuajok PHCC provide similar and additional information including: (1) lack of finacial resources – 50% of respondents; (2) traditional habits and presence of Traditional Birth Attendents in the community – 50% of respondents. Literature emphasises on the fact that health care systems experience the reality of staff shortages. Ilona Howard (as cited in Gordon, 2011) describes an average birth process where women usually go back to their original family home, where they then give birth with the help of their mother, and a Traditional Birthing Assistant (TBA). For these women, transport to a maternity clinic is often unaffordable, as are food costs during the stay - another reason why TBAs are so relied upon; (3) clinics have men midwives while women prefer to be assited by a woman – 50% of respondents; and (4) sometimes deliveries occur abruptly – 50% of respondents.

Other reasons evoked by pregnant women include the fact that some community members do not know anything about the existance of health facility; lack of health facility in the area as the consequence of war or lack of good services at health facility; deliveries also happen on the way to

health facility and culturally if there is no complication in delivery, no one would wonder about going to health facility. Some women also affirm have delivered at home their last born because it was their first pregnancy and they did not know when they were supposed to deliver. The literature confirm this point of view by emphasising the fact that health systems are weak as a result of conflict in South Sudan. Sarah Goldsmith (as cited in Gordon, 2011) added the fact that one of the main reasons women do not use clinics is also that they don't have confidence in them and are treated poorly when they go there. According to Gordon, maternal mortality is not only a medical problem. It is a problem inextricable from the lack of infrastructure and insufficient government-provided health staff and facilities.

Moreover, key informants at the Kuajok PHCC emphasided the fact that lack of awareness about benefits of a clinic is one of the major causes of such behavior and culturaly Dinka community fear hospital. In many cases, TBAs are also scaring women by telling them they will go through episiotomy at the clinic and the clinic will ask them for money. In the litterature, Gordon added the fact that maternal mortality is also due to failures in education and, essentially, inequality in the status of women. Unless women are acknowledged and valued beyond their child-bearing capacity and introduced to family-planning methods and education, the trajectory of maternal mortality rates will remain high.

4.4 Knowledge and attitudes about HIV/AIDS

The knowledge and attitudes about HIV/AIDS among respondents are presented in Table 4.5 below:

Table 4.5

Distribution of pregnant women according to their knowledge about HIV/AIDS

Have heard about HIV/AIDS	Frequency	Percent	Cum. Percent	95% CI Lower	95% CI Upper
Yes	23	77%	77%	58%	90%
No	7	23%	100%	10%	42%
TOTAL	30	100%	100%		

Most of pregnant women interviewed individually during the survey (77%) affirmed have heard about HIV/AIDS.

The information given above are graphically presented in Figure 4.5 below:

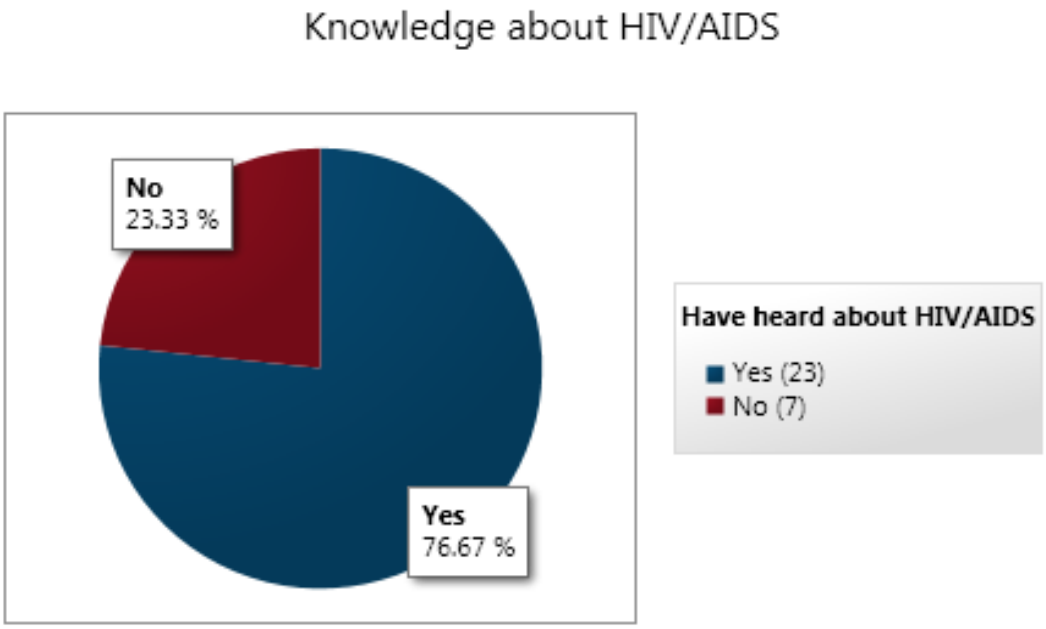

Figure 4.5. Distribution of respondents according to knowledge about HIV/AIDS

However, despite the large number of those who affirmed have heard about the disease, only 43% of them know that one can contract HIV through unprotected sex with an infected person and 9% affirmed through blood contact with infected blood. through breastfeeding. In addition, among those respondents, only 13% know that the virus can be transmitted from mother to child through breastfeeding and 22% do not know even one way someone can get infected.

The above-mentioned Figures are quite close to what is found in the litterature. Accordinding to International HIV/AIDS Alliance (2009), knowledge and awareness of HIV is very low in South Sudan, with only 45% of women between 15 and 45 having heard about it and 70% unaware of the three main forms of prevention. The majority of women (68% of 15-49 year-old women) don't have any knowledge that HIV can be transmitted from a mother to a child. UNICEF also confirms this point of view by saying that South Sudan has not had widespread dissemination of information on HIV and AIDS and therefore comprehensive knowledge about HIV transmission and prevention (11.3% among young people aged 15-24 years), as well as mother-to-child transmission, is very low (15.1%).

Other ways of HIV transmission evoked by some respondents include sharing of combs, having sex with a man who is not one's husband or sex outside marriage. All this show there is still some misconception, misunderstanding and misinterpretation about how someone can really get infected.

As opposite to individual interviews, 100% of participants in focus groups discussions affirmed have never heard about HIV/AIDS. This is probably linked to stigma associated with HIV bringing people to avoid open discussion about the disease when in a group. Phetoe (2011) emphasizes the fact that patients and health workers would not want to be associated with HIV & AIDS health care service due to the fear of stigma and, according to Sondergaard et al. (2010), one prominent reason usually given is that HIV and AIDS are associated with negative qualities such as "loose morals" and being a "prostitute".

Moreover, 50% of key informants interviewed at the Kuajok PHCC think that pregnant women who know to be HIV positive would prefer delivering at a health facility where their HIV status is not known because they feel ashamed and shy. Although all key informants affirmed there are cases of pregnant women who have tested HIV positive at the Kuajok PHCC and received counseling, 50% of them think that only few have delivered at a clinic for fear of being stigmatized. They added the fact that some pregnant women even think the clinician is a liar and prefer to go and find results elsewhere.

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

5.1 Conclusions

In the community surrounding the Kuajok PHCC, most pregnant women are still delivering at home. The major reasons evoked to explain such behavior include long distance to reach the nearest health facility, lack of financial resources among community members, poor transportation system, poor road infrastructures, traditional habits relying mostly on services provided by TBAs, limited awareness about how to take care of pregnancy, especially for those who are pregnant for the first time, misguiding messages spread within the community and poor awareness about the benefits of services provided at the clinical level.

Despite the fact that more pregnant women have heard about HIV/AIDS, most of them do not know the three ways of prevention and some misconceptions about HIV/AIDS are still a reality within the community. Stigma associated with the disease is also another live huge problem in Kuajok and surrounding areas which negatively contribute to inappropriate PMTCT service provision.

5.2 Recommendations

In order to provide proper PMTCT services in Kuajok PHCC and surrounding areas, a multi sectoral approach needs to be put in place involving different major stakeholders and state levels:

5.2.1 At the community level

Vast awareness campaigns to inform the community about the importance for pregnant women to attend antenatal care services need to be initiated and Behavior Change Communication (BCC) activities about HIV/AIDS and related to delivering in health facility need to be implementated at all levels. Knowing that behavior change takes some time to give effect, these activities should be implemented, not only for a very long period of time, but also should be kept continuous throughout.

5.2.2 At the humanitarian actors' level

Resources mobilization for an integrated MCNH-PMTCT is very key to:

1. Provide necessary capacity building and refreshment for health facility staff;
2. Provide behavior change communication within the community;

3. Ensure availability of essential drugs, materials and other related supplies to health facilities;
4. Support, for a for at least a certain period of time, the young South Sudan government in providing mobile clinical services to some extent in order to reach communities that cannot afford long distances to attend health facilities;
5. Work with both the community and the government to identify in the mean time low cost and local transportation alternatives like bicycle ambulances where approprite, etc;
6. Initiate and support the poor and most vulnerable communities in livelihood activities to make them self-reliant and be able to afford at least their basic needs in the future;
7. Analyze the potential to implement a pilot program to provide conditional cash transfers to pregnant women, based on their adherence to PMTCT services. Conditional cash transfers have been shown to be an effective incentive for targeted behavioral change; and
8. Advocate for the South Sudan government to allocate enough resources to the heath sector and prepare taking over interventions in the long run for more sustainability. Although the government policy is strict to stop TBAs from providing services in the community, in the current situation of South Sudan where most deliveries are still taking place at home, it will make sense to continue training TBAs in safe delivery, community PMTCT and appropriate referral to health facilities. This should be encouraged at least for a certain period of time and gradually phasing out as the government structures are taking place.

5.2.3 At the government level

Although the Government of South Sudan, both at the national and state level, is still young with a lot of challenges to overcome, a clear immediate, short term and long run plan needs to be in place and implemented step by step to better support PMTCT activities. It is therefore recommended for the Government to:

1. Work hand in hand with humanitarian actors to reinforce the capacity of existing health facilities in terms of staffing with appropriate skilled workers, rehabilitation of health facilities, regular provision of materials and supplies, integrated MCNH and PMTCT services as well as promotion of behavior change communication in the community;
2. Build step by step new health facilities close to the community according to the Ministry of Health norms, provide them with necessary equipment and resources and ensure they are continuously functional with integrated MCNH and PMTCT services free of charge at least for a certain period of time until when the country gets well organized;

3. Improve the transportation system as well as road infrastructures in order to make health facilities more accessible to the community, especially for individuals living in remote areas; and
4. Identify and implement any other innovative poverty reduction program and initiatives to ensure most of community members are self-reliant to address their basic needs at least in the near future.

REFERENCES

AIDS Support and Technical Assistance Resources (AIDSTAR-One). (2011). Integrating Prevention of Mother-To-Child Transmission of HIV interventions with Maternal, New-born and Child Health services. Retrieved April 1st, 2012, from http://www.aidstar-one.com/sites/default/files/AIDSTAR-One_TB_Integrating%20PMTCT%20with%20MNCH_0.pdf

Axios. (2007). Optimizing PMTCT through community outreach. Retrieved April 1st, 2012, from http://www.google.ht/search?sourceid=navclient&ie=UTF-8&rlz=1T4SKPB_enHT368HT374&q=TBAs+and+PMTCT

Cook Ross Inc. (2010). Background on Haiti & Haitian Health Culture. Retrieved April 1st, 2012, from http://www.cookross.com/docs/haiti.pdf

Dickinson, C., Attawell, K. & Druce, N. (2009). Progress on scaling up integrated services for sexual and reproductive health and HIV. Retrieved April 8, 2012, from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2770277/

Gordon, A. (2011). Maternal Mortality Remains an Obstacle for South Sudan. Retrieved June 20, 2012, from http://thinkafricapress.com/south-sudan/maternal-health-south-sudan

Government of South Sudan (GOSS) – Ministry of Health (undated). Prevention and treatment guidelines for Primary Health Care Units. Retrieved June 19, 2012, from http://documentsearch.org/read?=http://www.goss-online.org/magnoliaPublic/en/ministries/Health/mainColumnParagraphs/0/content_files/file3/Primary%20Health%20Care%20Units.PDF

International HIV/AIDS Alliance (2009). Preventing mother to child HIV transmission. Retrieved May 25, 2012, from http://www.aidsalliance.org/Newsdetails.aspx?Id=386

Joint United Nations Program on HIV/AIDS (UNAIDS). (2010). Getting to Zero. Retrieved April 12, 2012, from http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2010/JC2034_UNAIDS_Strategy_en.pdf

Joint United Nations Program on HIV/AIDS (UNAIDS). (2012). A guide to preventing mother-to-child transmission of HIV in the Caribbean. Retrieved April 12, 2012, from http://unaidscaribbean.org/node/221

Kabondo, C., Zimba, C., Kamanga, E., Hamela, G., Mofolo, I., Bulla, B., Martinson, F., Hoffman, I., Van der Horst, C & Hosseinipour, M. (2009). Evaluating the benefits of incorporating Traditional Birth Attendants in PMTCT service delivery in Lilongwe Semi-Urban District. Retrieved April 1st, 2012, from http://www.aegis.com/conferences/iashivpt/2009/MOAD104.html

Kamau, A.J. (Undated).Striving For Quality Care for PLWHA Amidst Poverty: A Review of Some Churches Effort in Soweto Slums, (Nairobi). Retrieved April 1st, 2012 from http://www.google.ht/search?sourceid=navclient&ie=UTF-8&rlz=1T4SKPB_enHT368HT374&q=pmtct+and+poverty

Michael, J., Andreini, M., Mojidi, K., Pressman, W., Rajkotia, Y. & Stanton, M.E. (2007). South Sudan maternal and reproductive health rapid assessment. Retrieved June 19, 2012, from http://documentsearch.org/read?=http://pdf.usaid.gov/pdf_docs/PNADN752.pdf

Michael, J & Garnett, G. (2010 - 2012). Special Supplement: Development of Nursing and Midwifery Services in South Sudan. Retrieved June 19, 2012, from http://www.southsudanmedicaljournal.com/archive/may-2011/special-supplement-development-of-nursing-and-midwifery-services-in-south-sudan.html

Phetoe, T. (2011). HIV stigma and PMTCT: Dilemmas faced by HIV positive mothers. Retrieved April 1st, 2012, from http://www.consultancyafrica.com/index.php?option=com_content&view=article&id=809:hiv-stigma-and-pmtct-dilemmas-faced-by-hiv-positive-mothers&catid=61:hiv-aids-discussion-papers&Itemid=268

Skinner, D., Mfecane, S., Gumede, T., Henda, N. & Davids, A. (2005). Barriers to accessing PMTCT services in a rural area of South Africa. Retrieved April 1st, 2012, from http://wwwisis.unam.na/hivdocs/skinner2005.pdf

Sondergaard, D.A., Hald, S.C. & Lazarus, J.V. (2010). Mother-to-child HIV transmission – stigma barrier to progress. Retrieved April 1st, 2012, from http://blogs.plos.org/speakingofmedicine/2010/05/20/mother-to-child-hiv-transmission-stigma-barrier-to-progress/

Thiam, S. (2012), Malaria in pregnancy: bringing maternal health and malaria communities together. Retrieved June 19, 2012, from http://maternalhealthtaskforce.org/discuss/wpblog/tag/south-sudan/

United Nation Children's Fund (UNICEF). (2012). Children in South Sudan. Retrieved June 19, 2012, from http://www.unicef.org/esaro/Children_in_South_Sudan_fact_sheets.pdf

World Health Organization (WHO). (2010). PMTCT Strategic Vision 2010 – 2015. Retrieved April 1st, 2012, from http://www.who.int/hiv/pub/mtct/strategic_vision.pdf

ADDENDA

Addendum A – Questionnaire for pregnant women attending ANC at Kuajok PHCC – South Sudan

Important: This survey is anonymous and participant identification (name and address) is not required.

Age of survey participant:

I. …….. years
II. Adult (As estimated by the researcher)

PART ONE: GENERAL QUESTIONS

1. In your community, where do most pregnant women usually deliver?
    a) At home/village
    b) At a health facility

2. If the response is **(a)** to question 1, what are the main reasons for such practice? Please get as many responses as possible.
    a) Long distance to reach the nearest health facility
    b) Lack of financial resources
    c) Lack of good services at the health facility
    d) Lack of transportation means
    e) Traditional habit
    f) Presence of TBAs in the community
    g) Other (specify): …….

PART TWO: QUESTIONS RELATED TO THE CURRENT PREGNANCY AND PAST PREGNANCIES

3. Have you delivered in the past before this pregnancy?
    a) Yes
    b) No

4. If the response is **(a)** to question 3, where did you delivered your last born?
    a) At home/village

b) At a health facility

5. If the response to question 4 is **(a)**, why didn't you deliver at a health facility? Please get as many answers as possible.
    a) Long distance to reach the nearest health facility
    b) Lack of financial resources
    c) Lack of good services at the health facility
    d) Lack of transportation means
    e) Traditional habit
    f) Presence of TBAs in the community
    g) Other (specify): ……

6. Where do you prefer to deliver this time?
    a) At home/village
    b) At a health facility

7. If the response to question 6 is **(a),** why do you prefer this option? Please get as many answers as possible.
    a) Long distance to reach the nearest health facility
    b) Lack of financial resources
    c) Lack of good services at the health facility
    d) Lack of transportation means
    e) Traditional habit
    f) Presence of TBAs in the community
    g) Other (specify): ……

PART THREE: QUESTIONS RELATED TO HIV/AIDS

8. Have you heard about HIV/AIDS?
    a) Yes
    b) No

9. If the answer to question 8 is **(a)**, what are the ways someone can contract HIV do you know? Please get as many answers as possible.

a) Unprotected sex with a person infected
b) Blood contact with infected blood
c) Breastfeeding
d) I don't know
e) Other (specify) ……

10. If the answer to question 9 is **(b)** and/or **(c)**, on your opinion, where do you think a pregnant women in your community who knows to be HIV positive would prefer to deliver?
    a) At home/village
    b) At a health facility

11. If the answer to question 10 is **(a)**, why do you think she would not prefer delivering at a health facility? Please get as many answers as possible.
    a) Lack of confidentiality at health facility
    b) Fear of being stigmatized
    c) Fear of discrimination
    d) Other (specify) ……

12. If the answer to question 10 is **(b)**, which type of health facility do you think she would prefer? Please guide the participant to choose one of the answers below.
    a) At a health facility where her HIV status is known.
    b) At a health facility where no one knows her HIV status
    c) At any health facility

13. If the answer to question 12 is **(a)**, why do you think she would prefer delivering at such health facility? Please get as many answers as possible.
    a) For better care
    b) Other (specify) ……

14. If the answer to question 12 is **(b)**, why do you think she would prefer delivering at such health facility? Please get as many answers as possible.
    a) To keep her HIV status confidential
    b) Other (Specify) ……...

Addendum B - Questionnaire for focus group discussions with pregnant women attending ANC at Kuajok PHCC – South Sudan

Important: This survey is anonymous and participant identification (name and address) is not required.

PART ONE: GENERAL QUESTIONS

1. In your community, where do most pregnant women usually deliver?
    a) At home/village
    b) At a health facility

2. If the response is **(a)** to question 1, what are the main reasons for such practice? Please get as many responses as possible.
    a) Long distance to reach the nearest health facility
    b) Lack of financial resources
    c) Lack of good services at the health facility
    d) Lack of transportation means
    e) Traditional habit
    f) Presence of TBAs in the community
    g) Other (specify): …….

PART TWO: QUESTIONS RELATED TO HIV/AIDS

3. Have you heard about HIV/AIDS?
    a) Yes, for the majority of participants
    b) No, for the majority of participants
    c) Never

4. If the answer to question 3 is **(a)**, what are the ways someone can contract HIV do you know? Please get as many answers as possible.
    a) Unprotected sex with a person infected (for the majority of participants)
    b) Blood contact with infected blood (for the majority of participants)
    c) Breastfeeding (for the majority of participants)
    d) I don't know (for the majority of participants)
    e) Other (specify) ……

5. If the answer to question 3 is **(b)** and/or **(c)**, on your opinion, where do you think a pregnant women in your community who knows to be HIV positive would prefer to deliver?
    a) At home/village (for the majority of participants)
    b) At a health facility (for the majority of participants)

6. If the answer to question 5 is **(a)**, why do you think she would not prefer delivering at a health facility? Please get as many answers as possible.
    a) Lack of confidentiality at health facility (for the majority of participants)
    b) Fear of being stigmatized (for the majority of participants)
    c) Fear of discrimination (for the majority of participants)
    d) Other (specify) ……

7. If the answer to question 5 is **(b)**, which type of health facility do you think she would prefer? Please guide the participants to choose one of the answers below.
    a) At a health facility where her HIV status is known (for the majority of participants).
    b) At a health facility where no one knows her HIV status (for the majority of participants).
    c) At any health facility (for the majority of participants).

8. If the answer to question 7 is **(a)**, why do you think she would prefer delivering at such health facility? Please get as many answers as possible.
    a) For better care (for the majority of participants).
    b) Other (specify) ……

9. If the answer to question 7 is **(b)**, why do you think she would prefer delivering at such health facility? Please get as many answers as possible.
    a) To keep her HIV status confidential (for the majority of participants).
    b) Other (specify) ……

Addendum C - Questionnaire for key informant personnel working at Kuajok PHCC – South Sudan

Important: This survey is anonymous. Please do not provide names and addresses of people concerned by this survey questionnaire.

I. Number of months/years being working at Kuajok PHCC: ……..

II. Number of months/years being working in this position: ……

PART ONE: GENERAL QUESTIONS

1. In your community, where do most pregnant women usually deliver?
   a) At home/village
   b) At a health facility

2. If the response is **(a)** to question 1, what are the main reasons for such practice? Please get as many responses as possible.
   a) Long distance to reach the nearest health facility
   b) Lack of financial resources
   c) Lack of good services at the health facility
   d) Lack of transportation means
   e) Traditional habit
   f) Presence of TBAs in the community
   g) Other (specify): …….

PART TWO: QUESTIONS RELATED TO HIV/AIDS

3. Do you have cases of pregnant women who have been tested HIV positive in this clinic?
   a) Yes
   b) No

4. If the answer to question 3 is **(a)**, are those HIV positive been told and counseled about their HIV status? Please get one answer only.
   a) Yes for all
   b) Some only
   c) No

5. If the answer to question 4 is **(a)**, how many of them do you think have delivered at a clinic? Please get one answers only.
    a) Almost all
    b) Some only
    c) Few of them only
    d) None

6. If the answer to question 5 is **(b)** and/or **(c)** and/or **(d)**, why do you think they would not prefer delivering at a health facility? Please get as many answers as possible
    a) Lack of confidentiality at health facility
    b) Fear of being stigmatized
    c) Fear of discrimination
    d) Other (specify) ……

7. If the answer to question 5 is **(a)** and/or **(b)** and/or **(c)**, which type of health facility do you think HIV positive pregnant women who know their status would prefer? Please guide the participant to choose one of the answers below.
    a) At a health facility where their HIV status is known
    b) At a health facility where no one knows their HIV status
    c) At any health facility

8. If the answer to question 7 is **(a)**, why do you think they would prefer delivering at such health facility? Please get as many answers as possible.
    a) For better care
    b) Other (specify) ……

9. If the answer to question 7 is **(b)**, why do you think they would prefer delivering at such health facility? Please get as many answers as possible.
    a) To keep their HIV status confidential
    b) Other (specify) ……

Addendum D – Informed consent form for pregnant women

UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

UNDERSTANDING BARRIERS FOR PREGNANT WOMEN, ESPECIALLY THOSE WHO MIGHT BE HIV POSITIVE TO DELIVER AT A CLINIC – A RESEARCH CASE OF KUAJOK PRIMARY HEALTH CARE CLINIC IN GOGRIAL WEST COUNTY – WARRAP STATE – SOUTH SUDAN

You are asked to participate in a research study conducted by Dr. Leonardo Shamamba Kinyungu, from the Africa Centre for HIV/AIDS Management at Stellenbosch University. Results will be contributed to research paper. You were selected as a possible participant in this study because you are a pregnant woman aged 18 years or above attending antenatal care at Kuajok Primary Health Care Clinic.

1. PURPOSE OF THE STUDY

The purpose of this research is to identify what are the barriers for pregnant women in general and for those who might be HIV positive, in particular, to deliver at the clinic in order to develop appropriate strategies to address this issue.

2. PROCEDURES

If you volunteer to participate in this study, we would ask you to respond to questions that will be administered by Dr. Leonardo Shamamba with the support of the nurse who is working in this clinic. The nurse will be the translator. The process will take approximately 15 to 20 minutes.

3. POTENTIAL RISKS AND DISCOMFORTS

There will be a potential risk of discomfort as the researcher will be asking some of your personal information regarding certain practices and your general knowledge about HIV. But feel free not to respond to a question that you think is embarrassing to you. Not responding to a question does not have any negative impact on you as a participant. Should any discomfort like the one described above happens, a nurse from Kuajok PHCC will take time with you and provide necessary counseling services to minimize this risk.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Pregnant women and new born will benefit in such a way results from this study will suggest strategies to minimize unsafe deliveries as well as new HIV infection in children. The study will also benefit the entire family since the outcome will suggest how to have a healthy family despite the parents' HIV positive status and minimize economic burden on the family related to complications of pregnancies. Moreover, the study will also benefit the health care providers since the outcome will suggest ways to reduce the number of complicated deliveries and HIV pediatric cases to deal with in the future.

5. PAYMENT FOR PARTICIPATION

There will be no payment to participants in this study.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of not recording names and addresses of participants on the questionnaire forms. After the survey, all the forms will be enclosed for three years in a cabinet that only the researcher has access to keys. All the forms will be destroyed after 3 years. Only authorized people like the researcher or nurses in this clinic will have the key to access information related to this study stored on a computer machine.

The results of this study will be made available to Health Care authorities, the nurses in this Clinic and Organizations that provide support to clinics in this state. The purpose of providing the results to these entities is to let them mobilize appropriate resources and strategies to address issues that will be discovered in the study. Since the names and addresses of participants will not be recorded on the questionnaire forms, no one will be able to personally identify people who participated. Only the general results will be made available to the above mentioned entities.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to participate in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so (e.g. if the researcher feels that you are not comfortable to be part of the study or you do not have enough time to participate from the beginning to the end, etc.).

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Dr. Leonardo Shamamba Kinyungu (Leonardo_shamamba@yahoo.fr or call at +211-928-831-635).

9. RIGHTS OF RESEARCH SUBJECTS

You may refuse to continue participating in this study at any time and discontinue participation without penalty. The fact of participating in this study does not mean you have rights to remedies or legal claims. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to me by Dr. Leonardo Shamamba Kinyungu in English and satisfactory translated by …… in Dinka and I am in command of this language. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

_____

Name of Subject/Participant

_____

Name of Legal Representative (if applicable)

_____ _____

Signature of Subject/Participant or Legal Representative **Date**

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____. She was encouraged and given ample time to ask me any questions. This conversation was conducted in English and was translated into _____ by _____.

_____ _____

Signature of Investigator **Date**

SIGNATURE OF SUPERVISOR

_____ _____

Signature of Supervisor Date

Prof Johan Augustyn

jcda@sun.ac.za

Addendum E – Informed consent form for participants in focus group discussions

UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

UNDERSTANDING BARRIERS FOR PREGNANT WOMEN, ESPECIALLY THOSE WHO MIGHT BE HIV POSITIVE TO DELIVER AT A CLINIC – A RESEARCH CASE OF KUAJOK PRIMARY HEALTH CARE CLINIC IN GOGRIAL WEST COUNTY – WARRAP STATE – SOUTH SUDAN

You are asked to participate in a research study conducted by Dr. Leonardo Shamamba Kinyungu, from the Africa Centre for HIV/AIDS Management at Stellenbosch University. Results will be contributed to research paper. You were selected as a possible group of participants in this study because you are pregnant women aged 18 years or above attending antenatal care at Kuajok Primary Health Care Clinic.

1. PURPOSE OF THE STUDY

The purpose of this research is to identify what are the barriers for pregnant women in general and for those who might be HIV positive, in particular, to deliver at the clinic in order to develop appropriate strategies to address this issue.

2. PROCEDURES

If you volunteer to participate in this study, we would ask each of you to actively participate in the discussion chaired by Dr. Leonardo Shamamba with the support of the nurse who is working in this clinic. The nurse will be the translator. The process will take approximately 30 to 45 minutes.

3. POTENTIAL RISKS AND DISCOMFORTS

There will be a potential risk of discomfort as the researcher will be asking for some information regarding certain practices and general knowledge about HIV in your community. But feel free not to respond to a question that you think is embarrassing to you. Not responding to a question does not have any negative impact on you as a participant. Should a discomfort like the one described above happens, a nurse from Kuajok PHCC will take time with the group and provide necessary counseling services to minimize this risk.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Pregnant women and new born will benefit in such a way results from this study will suggest strategies to minimize unsafe deliveries as well as new HIV infection in children. The study will also benefit the entire family since the outcome will suggest how to have a healthy family despite the parents' HIV positive status and minimize economic burden on the family related to complications of pregnancies. Moreover, the study will also benefit the health care providers since the outcome will suggest ways to reduce the number of complicated deliveries and HIV pediatric cases to deal with in the future.

5. PAYMENT FOR PARTICIPATION

There will be no payment to participants in this study.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of not recording names and addresses of participants on the questionnaire forms. After the survey, all the forms will be enclosed for three years in a cabinet that only the researcher has access to keys. All the forms will be destroyed after 3 years. Only authorized people like the researcher or nurses in this clinic will have the key to access information related to this study stored on a computer machine.

The results of this study will be made available to Health Care authorities, the nurses in this Clinic and Organizations that provide support to clinics in this state. The purpose of providing the results to these entities is to let them mobilize appropriate resources and strategies to address issues that will be discovered in the study. Since the names and addresses of participants will not be recorded on the questionnaire forms, no one will be able to personally identify people who participated. Only the general results will be made available to the above mentioned entities.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to participate in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so (e.g. if the researcher feels that you are not comfortable to be part of the study or you do not have enough time to participate from the beginning to the end, etc.).

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Dr. Leonardo Shamamba Kinyungu (Leonardo_shamamba@yahoo.fr or call at +211-928-831-635).

9. RIGHTS OF RESEARCH SUBJECTS

You may refuse to continue participating in this study at any time and discontinue participation without penalty. The fact of participating in this study does not mean you have rights to remedies or legal claims. If you have questions regarding your rights as a research subject, contact Ms. Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to me by Dr. Leonardo Shamamba Kinyungu in English and satisfactory translated by …… in Dinka and I am in command of this language. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

_____

Name of Subject/Participant

_____

Name of Legal Representative (if applicable)

_____ _____

Signature of Subject/Participant or Legal Representative **Date**

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [*name of the subject/participant].* She was encouraged and given ample time to ask me any questions. This conversation was conducted in English and was translated into _____ by _____.

_____ _____

Signature of Investigator **Date**

SIGNATURE OF SUPERVISOR

_____ _____

Signature of Supervisor Date

Prof Johan Augustyn

jcda@sun.ac.za

Addendum F – Informed consent form for key informant at Kuajok PHCC

UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

UNDERSTANDING BARRIERS FOR PREGNANT WOMEN, ESPECIALLY THOSE WHO MIGHT BE HIV POSITIVE TO DELIVER AT A CLINIC – A RESEARCH CASE OF KUAJOK PRIMARY HEALTH CARE CLINIC IN GOGRIAL WEST COUNTY – WARRAP STATE – SOUTH SUDAN

You are asked to participate in a research study conducted by Dr. Leonardo Shamamba Kinyungu, from the Africa Centre for HIV/AIDS Management at Stellenbosch University. Results will be contributed to research paper. You were selected as a possible participant in this study because you are a health worker at Kuajok Primary Health Care Clinic.

1. **PURPOSE OF THE STUDY**

The purpose of this research is to identify what are the barriers for pregnant women in general and for those who might be HIV positive, in particular, to deliver at the clinic in order to develop appropriate strategies to address this issue.

2. PROCEDURES

If you volunteer to participate in this study, we would ask you to respond to questions that will be administered by Dr. Leonardo Shamamba Kinyungu at the Kuajok PHCC. The process will take approximately 15 to 20 minutes.

3. POTENTIAL RISKS AND DISCOMFORTS

There will be a potential risk of discomfort as the researcher will be asking information regarding community perception and certain practices in your clinic related to HIV. But feel free not to respond to a question that you think is embarrassing to you. Not responding to a question does not have any negative impact on you as a participant.

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

Pregnant women and new born will benefit in such a way results from this study will suggest strategies to minimize unsafe deliveries as well as new HIV infection in children. The study will also benefit the entire family since the outcome will suggest how to have a healthy family despite the parents' HIV positive status and minimize economic burden on the family related to complications of pregnancies. Moreover, the study will also benefit the health care providers since the outcome will suggest ways to reduce the number of complicated deliveries and HIV pediatric cases to deal with in the future.

5. PAYMENT FOR PARTICIPATION

There will be no payment to participants in this study.

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of not recording names, addresses and position of participants on the questionnaire forms. After the survey, all the forms will be enclosed for three years in a cabinet that only the researcher has access to keys. All the forms will be destroyed after 3 years. Data on electronic forms will be protected by a password that only authorized people will have access to.

The results of this study will be made available to the Primary Health Care authorities, the head of the Kuajok Primary Health Care Clinic and Non-Governmental Organizations. The purpose of providing the results to these entities is to let them mobilize appropriate resources and strategies to address issues that will be discovered in the study. Since this study will be anonymous and confidential, no one will be able to personally identify any participant. Only the general results will be made available.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact Dr. Leonardo Shamamba Kinyungu (Leonardo_shamamba@yahoo.fr or call at +211-928-831-635).

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms. Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to me by Dr. Leonardo Shamamba Kinyungu in English and I am in command of this language. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

_____

Name of Subject/Participant

_____

Name of Legal Representative (if applicable)

_____ _____

Signature of Subject/Participant or Legal Representative **Date**

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [*name of the subject/participant].* She was encouraged and given ample time to ask me any questions. This conversation was conducted in English.

_____ _____

Signature of Investigator **Date**

SIGNATURE OF SUPERVISOR

_____ _____

Signature of Supervisor Date

Prof Johan Augustyn

jcda@sun.ac.za